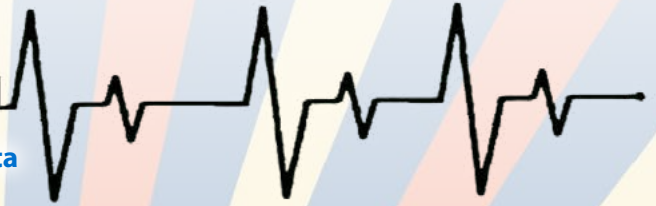


Parkinson PULSE

Connecting people living with Parkinson disease in Alberta



Non-Motor Symptoms of Parkinson Disease

**GREATEST
HITS**

VOLUME 1



FLEXXAIRE

The reversible fan for diesel engines.

**Proud supporter of
Parkinson Association of Alberta**

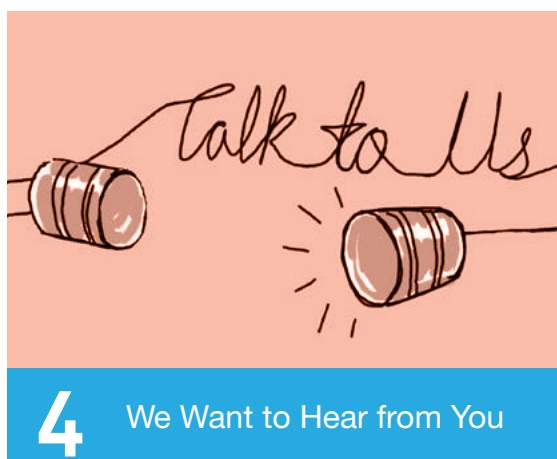
#StepNStride



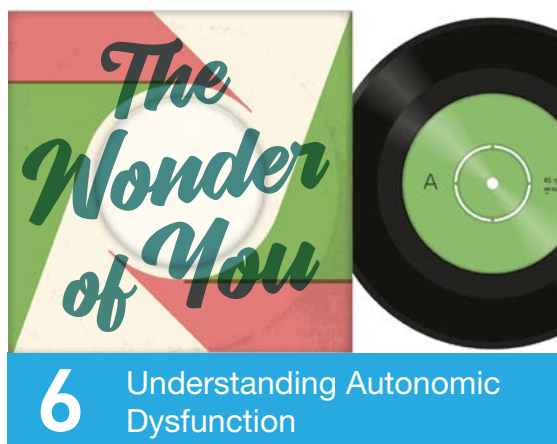
OUTDOOR SUMMER SOCIALS ARE BACK!!

Call 1-800-561-1911 or a Client Services Coordinator for more details or to register!





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Summer 2021

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Parkinson Association of Alberta is the voice of Albertans and their families living with Parkinson disease. Our purpose is to ease the burden through advocacy, education, client services and find a cure through research.

We welcome your comments, suggestions and questions. Email us at communications@parkinsonassociation.ca; or call us toll-free at **1-800-561-1911**.

Parkinson Pulse is available (both past and present issues) as a free download via our website. Hard copies are available for mail out to current Members who wish to receive one.

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Articles and information contained in the Parkinson Pulse are provided solely for the readers' interest. Articles do not necessarily reflect the views of Parkinson Association of Alberta and are NOT intended as medical advice. Please consult your doctor or neurologist in all matters relating to health concerns or medication.

Would you like to see your company ad in the **Parkinson Pulse**?

Advertising rates and opportunities are available.

Contact:
communications@parkinsonassociation.ca





I had the privilege of talking with and learning from one of our very active clients last month. Thinking about the subject of this edition of Pulse Magazine - Non-Motor Symptoms - I reflect on Cathy's story. Those around Cathy, whether at work, home or out in the community, couldn't see what she was experiencing. She didn't present with tremors or dyskinesia or other common visual symptoms of Parkinson's. People diagnosed with Parkinson disease or Parkinson's Plus Syndromes experience such a variety of motor and non-motor symptoms at very different stages of their journey that it becomes much easier to retreat from the things we enjoy than to reach out. You aren't alone.

We hope you find some new and helpful learnings in the pages that follow and gain some comfort in knowing the team at Parkinson Association is here when you need us.

As restrictions ease in our province and around the world, we look forward to spending time with you again in our upcoming outdoor socials. We also are busy planning for resumption of in-person activities and support this fall, while maintaining the popular virtual programming you've grown accustomed to. We are truly grateful to each of you who took the time to respond to our recent survey; we will continue to be diligent in ensuring the safety and comfort of our community remains our top priority.

We look forward to sharing with you, our plans for the 9th Annual Flexxaire Parkinson Step'n Stride! When circumstances required us to go virtual last year, our community continued to demonstrate their commitment. We are so grateful and even more excited to come back together this year in person! Mark your calendars for September 11 and 12 and watch for more information on a hybrid virtual and in-person version of "walk" in your community.

From all of us at Parkinson Association of Alberta, I wish you a peaceful and enjoyable summer.

Lana Tordoff,
Executive Director

JOIN OUR CIRCLE OF HELP



GIVE A GIFT

Text **HOPE** to 80100 to donate \$10 or
\$25 to Parkinson Association of
Alberta



SHARE ON SOCIAL MEDIA

Tag us and use the #circleofhelp



BECOME A MEMBER

Join our safe and caring
community of support.

We Want to Hear from You

The challenges and success you share helps others. It is for you and because of you that we learn and grow as a staff and as a part of the Parkinson's community. The conversations you have with us, the insights you share and the feedback you provide us, helps create the path forward...together.

We would love to receive more feedback from you on our magazines – be it the issue as a whole or a specific article. Did something you read help you? Did you not care for a particular article? (It's ok, honest we want to know!) It is always our sincere hope that each issue will offer readers some level of insight or knowledge, AND start conversations be it at home or with peers! Below we share some feedback we received for our Spring 2021 issue "Home is Where the Heart is...Navigating Housing Transitions" issue.



First I have to thank and praise Lana, Brienne, Declan, Emma, Ashley, Sherry and of course Brandi on your good work on the Spring 2021 Pulse magazine. This past year it became evident that we could not carry on without serious help so come Fall 2020 we contacted AHS looking to be admitted to the Choice program. We were accepted in January into that program and down the slide we went. January and most of February we tried working with Choice but we soon found out we had passed that stage where they could help.



The days leading up to February 28 were very difficult at home. I wasn't very smart in that the train had fallen off the rails and I was still trying to push it along. Five in the morning of February 28 we ended up at the Sherwood Park hospital where we received good care but the doctor suggested we needed more and recommended we go to the University or Grey Nun's hospital. Naturally I turned him down since I was doing so good pushing the train on my own. The next morning at ten I phoned 911 and had my Colette transported to the University hospital where she spent the next three weeks being poked and prodded and assessed. They assessed Colette needing LTC and she was moved to a transition ward till we got the placement we wanted at Capital Care Dickinsfield on March 20.

Three weeks later, and we have celebrated Easter and my birthday in Colette's new home, we survived the two weeks mandatory isolation and an extra week in fear to leave the room. Now as you see in the last picture, Colette has made it to the common areas and is eating in the dining room.



The pictures do not show the dark moments we had during this transition. We are trying to stay positive and adjust to our new life. We have been through many of the steps you describe in the magazine and I am sure your detailed descriptions of the many options will be very helpful to others. Again, thank you for all you done for us and we look forward to seeing all of you once this darn Pandemic permits us.

Ed & Colette Langevin

Your feedback, comments, and insights are ALWAYS welcome! In fact, we would like to highlight them (as we've done here) in future magazines. Share your feedback with your Client Services Coordinator, **call us toll-free** at 1-800-561-1911, or **email us** at communications@parkinsonassociation.ca.



Written By: **Brandi La Bonte**

Remember “Greatest Hits” albums (or cassettes or CDs or Spotify playlists – depending on which generation you grew up in)? You know the ones that had a bunch of different songs compiled together in one convenient location? In trying to find a theme for this issue – Non-motor Symptoms in Parkinson’s – it’s the visual that kept popping into my head. I know what you might be thinking – that seems like a leap, there is nothing “great” about non-motor symptoms. You are correct, and yet I hope you will indulge my creativity for this issue.

You see there are so many non-motor symptoms, more than can be tackled in any one 24-page magazine. Unsure where to begin or what to include, I started making a list, that list started to visually resemble tracks on an album, and then song titles loosely related to the articles began popping in my head... and here we are. Though the song titles may seem a bit less serious, I assure you every article was approached (as always) with the utmost respect and dedication to providing clear, concise and factual information to you our readers. With that in mind, let’s begin.

Parkinson disease is primarily thought of as a **movement** disorder with symptoms that one can see – tremor, slowed movement (bradykinesia), rigidity/stiffness and postural instability. However, there is a host of other symptoms that do not affect movement and are much harder (if not impossible) to see. These are known as **non-motor symptoms** and they encompass a wide range of health concerns:

Autonomic dysfunction

This one is vast in and of itself covering a host of vital bodily functions including (but not limited to) blood pressure, heart rate, sweating, dry mouth, drooling, loss of sense of smell or taste, digestion, bladder and bowel problems, and sexual functions to name a few. In this issue we focus heavily (but not exclusively) on symptoms that fall into this category.

Mood, thinking and psychological issues

Mood disorders (such as anxiety, depression and apathy), cognitive issues, dementia and hallucinations can play a role, to varying degrees, in life with Parkinson’s.

Sleep issues

From excessive daytime sleepiness to insomnia, sleep issues are considered an inherent part of Parkinson’s with prevalence rates ranging from 75-98% within the Parkinson’s population.

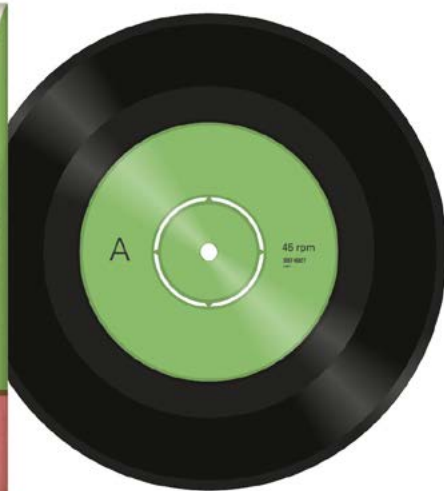
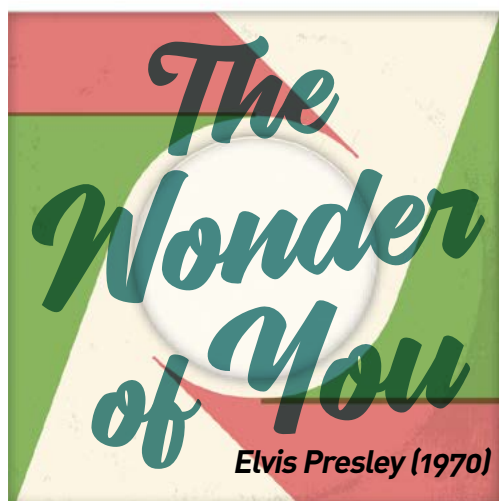
Speech and Swallowing Issues

For people with Parkinson disease or Parkinson’s Plus Syndromes, the seemingly simple acts of speech and swallowing are not something that can be taken for granted. From a softening of the voice (hypophonia) to an abnormally fast rate of speaking, to difficulties swallowing there are a host of problems that may emerge.

Issues with vision, foot dystonia and fatigue are also considered non-motor symptoms. These behavioural, neuropsychiatric and physical symptoms can occur at any point in one’s Parkinson’s journey. Across the international Parkinson’s community, non-motor symptoms are often reported to have a bigger impact on one’s quality of life than the motor symptoms themselves.

Due to the broad number of non-motor symptoms, there is no ONE way to treat them as each symptom typically needs to be addressed individually. It is so very important to make note of any symptoms you may be experiencing and talk to your doctor.

I hope this issue provides a beneficial start to understanding non-motor symptoms and I look forward to creating Volume 2 with the Team!



Understanding Autonomic Dysfunction

Written By: **Brandi La Bonte**

Autonomic dysfunction is a common non-motor symptom of Parkinson disease and the result of a breakdown in the autonomic nervous system. Ok, sure. Let's simplify, shall we. To understand autonomic dysfunction, one must first understand some brain and nervous system basics. So, let's start with the basics.

The brain is our body's control or command center. Our brains control everything we do, from movement, speech, and our senses; to basic bodily functions and aspects of our personalities. To carry out the various commands (automatic and thoughtful ones) the brain is constantly directing messages and receiving feedback through a complex network of nerves (nervous system) that travel throughout our entire body.

Our nervous system is divided into two parts: the central and peripheral nervous systems. The brain and spinal cord make up the **central nervous system**, while the **peripheral nervous system** includes all the nerves that branch out from the brain and spinal cord. Still with me? Good!

The peripheral nervous system is also divided into two parts, the somatic and autonomic nervous systems. The **somatic nervous system** is responsible for receiving and sending sensory (think your five senses) and motor (think voluntary muscle movements ie: throwing, walking, etc.) information. The **autonomic nervous system** is responsible for all the involuntary, and often vital, functions of our bodies, including breathing, heart rate, blood pressure, pupil dilation, digestion, urination, temperature control, and sexual function.

As I mentioned earlier autonomic dysfunction is a breakdown in the autonomic nervous system, so it is here we will focus a little more attention. Understanding the system itself, makes it easier to understand what and why certain functions aren't working properly.

There are two main parts to the autonomic nervous system: the sympathetic and the parasympathetic nervous systems. In the simplest of terms these two systems function as mirror opposites of each other. Each one is responsible for either automatic/involuntary responses to negative (distress)/positive (eustress) stress OR day-to-day function/recovery.

The **sympathetic nervous system** is your body's stress response center; think fight or flight response. To be clear this can be a response to negative (danger, anger, etc) or positive (excitement, anticipation, etc) stress. In anticipation of a perceived or actual stressor your body automatically starts to make changes. Breathing and heartbeat increase in order to provide our body with the energy and oxygen it needs to fuel a rapid response. Blood flow to the surface areas of the body is reduced



while flow to other areas (ie: muscles, brain, legs, etc) is increased. Digestion slows down and adrenaline kicks in.

The **parasympathetic nervous system** is your body's housekeeping and recovery centre; in this case think rest and digest. In order for your body to recover and/or maintain optimal function the parasympathetic nervous system will automatically engage the necessary day-to-day bodily functions. For example, heart rate and breathing slows down, our digestive system kicks into gear (saliva and bile production, movement of the stomach and intestines) providing both fuel and removing waste. Blood flows freely to all parts of the body.

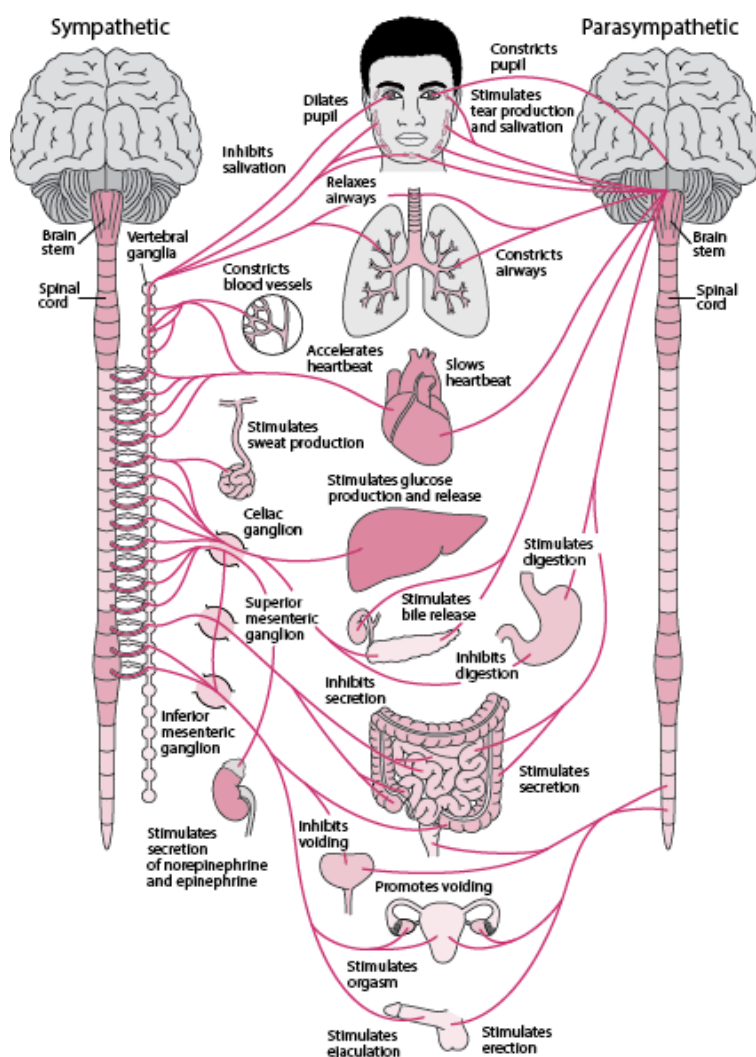
The changes our bodies automatically make within these mirrored systems are meant to optimize our functioning. Take blood pressure. Our body is constantly monitoring to see if it needs to raise or lower our blood pressure; if there is a threat our blood pressure rises and when the threat is gone or it's time to go to sleep, our blood pressure lowers. Or consider sex, the parasympathetic system is responsible for erection, while the sympathetic system is responsible for orgasm and ejaculation.

Typically, the parasympathetic and sympathetic nervous systems are in perfect balance, from moment to moment, depending on the body's instantaneous needs. When the system isn't functioning normally you can face a number of bodily dysfunctions that affect your health. This breakdown is called autonomic dysfunction (also known as dysautonomia).

Symptoms of autonomic dysfunction in Parkinson's can include (but are not limited to): frequent aches and pains, numbness and tingling, dizziness, fainting, blurred vision and/or dry eyes, bladder problems, constipation, fatigue, low blood pressure, loss of sense of smell and/or taste, swallowing and/or drooling issues, excessive sweating and increased sensitivity to heat/cold, and sexual dysfunction.

What causes autonomic dysfunction in Parkinson disease?

The autonomic nervous system is directly affected by neurodegeneration and Lewy body-like accumulations. Autonomic dysfunction often occurs in Parkinson's due to the loss of dopamine-producing cells and the presence of microscopic protein deposits called Lewy bodies in the brain. As a result, a number of non-motor symptoms may be experienced. Research suggests that the peripheral nervous system may be affected long



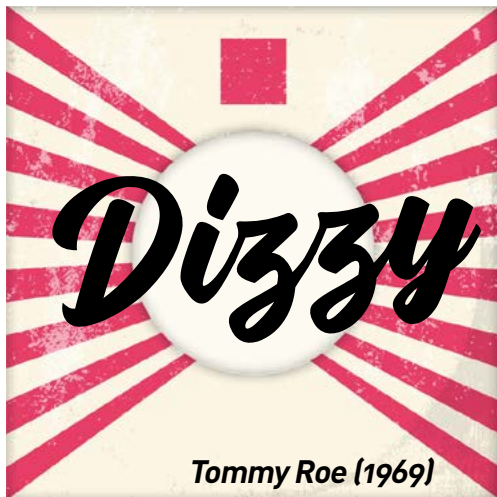
before such symptoms appear.¹ Research also indicates that some medications used to treat Parkinson's can also affect the autonomic nervous system. If autonomic dysfunction is severe, a Parkinson's Plus Syndrome, such as multiple system atrophy (MSA), may be present.

What can you do about it?

Treatment will depend on the type of autonomic dysfunction you are experiencing. More information on the different types of autonomic dysfunction can be found throughout this magazine, on our website (parkinsonassociation.ca) and by talking to your Client Services Coordinator. Always be sure to discuss any and all symptoms you may be experiencing with your treating physician.

References

¹ European Parkinson's Disease Association (EPDA). <https://www.epda.eu.com/about-parkinsons/symptoms/non-motor-symptoms/autonomic-dysfunction/>



Orthostatic Hypotension

Written By: **Brandi La Bonte**

Vital signs reflect fundamental body functions and are an essential part of monitoring a person's overall health. Pulse, respiratory rate, temperature, and blood pressure are four of a person's key vital signs. Normal vital signs can change with age, sex, weight, exercise capability, and overall health.

Normal vital sign ranges for an average healthy adult while resting are:

- Pulse: 60 to 100 beats per minute
- Breathing: 12 to 18 breaths per minute
- Temperature: 36.5°C/97.8°F to 37.3°C/99.1°F
Average is 37°C/98.6°F
- Blood Pressure: 90/60 mm Hg to 120/80 mm Hg

In this particular article we are going to focus on blood pressure, specifically orthostatic hypotension, and its connection to Parkinson disease. Medically speaking, orthostatic hypotension (also known as postural hypotension) is a "physical finding defined by

the American Autonomic Society and the American Academy of Neurology as a systolic blood pressure decrease of at least 20 mm HG or a diastolic pressure decrease of at least 10mm Hg within three minutes of standing."¹

Huh? In layperson's terms, orthostatic hypotension is a significant drop in blood pressure that may happen when a person changes positions, for example stands up from sitting or lying down. In addition to putting the person experiencing it at a greater risk of falls and injury, orthostatic hypotension can cause:

- light-headedness
- dizziness
- weakness
- fatigue
- nausea
- headache or neck pain
- blurred vision or a narrowing of your field of vision (tunneling)
- difficulty concentrating
- or, if severe, fainting or a loss of consciousness



If you or your loved one are experiencing any of these symptoms it is best to sit or lie down and wait for the feelings mentioned above to disappear.

What causes orthostatic hypotension?

It is important to note that there are many possible causes for low blood pressure beyond Parkinson disease. Dehydration, anemia, high blood pressure medications, diabetes, heart conditions and prolonged immobility are a few examples. There is a connection to Parkinson's however as this form of low blood pressure happens in about one third of people with Parkinson's. Why? Well Parkinson disease adversely affects the autonomic nervous

system (as discussed on page 6); impairing the body's natural ability to regulate automatic functions like blood pressure when changing positions, exercising, eating or being outside in warm weather. Additionally, some Parkinson's medications may also cause orthostatic hypotension or make it worse.

For people with Parkinson disease orthostatic hypotension may be more common when doing activities that require an increased demand for blood.

- after a quick change in position (most commonly when moving from a lying down to a sitting or standing position)
- in the morning (blood volume is typically lower and you have been laying flat for an extended period of time)
- after or during activities that involve physical exertion
- after meals (especially big meals as more blood is needed by the digestive system)
- after drinking alcohol
- when urinating or having a bowel movement (especially if constipated, the effort of straining lowers blood pressure)
- in a warm environment – ie: hot weather, a hot bath or shower (as the distribution of blood throughout your body increases due to the dilation of blood vessels)

Managing orthostatic hypotension

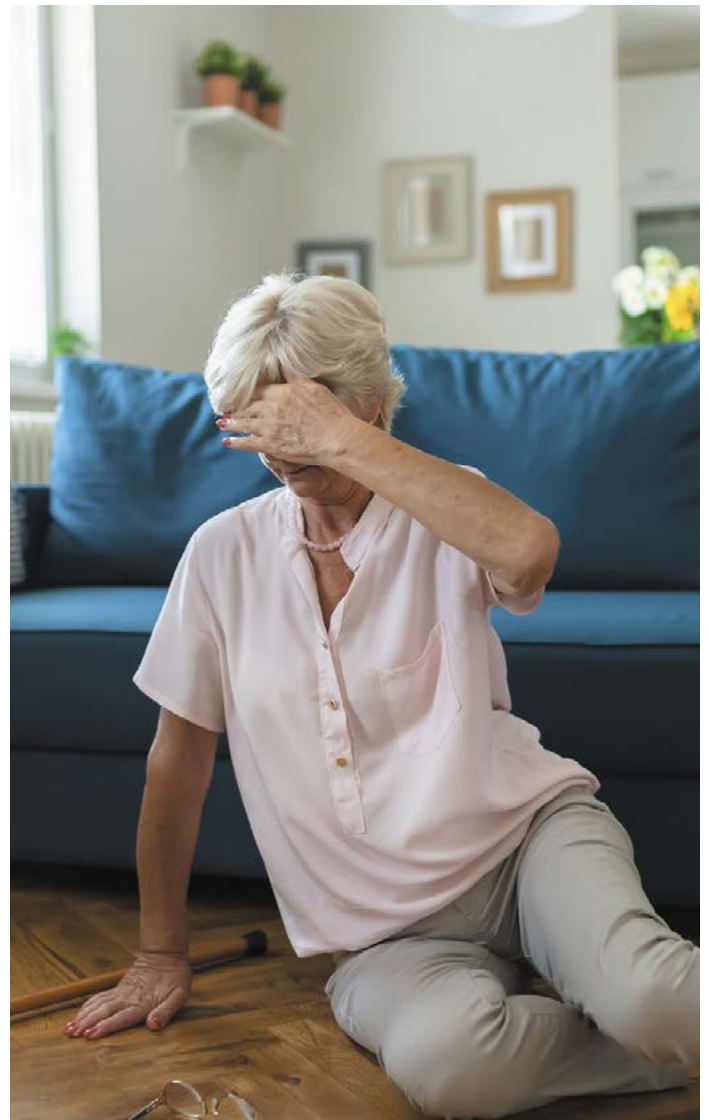
The good news is orthostatic hypotension can often be managed quite effectively. How your doctor treats your orthostatic hypotension will depend on your symptoms and/or what is causing your low blood pressure. Medication changes or additions, compression devices and/or lifestyle adjustments may be recommended.

Some lifestyle adjustments may include:

- taking your time when changing positions, particularly from sitting or laying to standing
- drinking 8ozs/1 cup of cold water BEFORE standing up or getting out of bed in the mornings
- drinking more fluids overall to stay hydrated
- try having frequent, but smaller meals over the course of the day
- be sure to hold onto something when bending or reaching for items

- do not stay in a warm environment for too long and try to avoid doing unnecessary activities in hot weather
- try elevating your head with pillows or the entire head of the bed if possible when laying down
- engage in regular exercise, if you don't typically exercise, start small and while seated
- avoid standing or sitting still for long periods of time; if you can't then be sure to shift your position and/or cross and uncross your legs every so often

If you or your loved one think you may be experiencing orthostatic hypotension be sure to talk to your doctor as they will be able to find the best treatment option for you.



References

¹ Consensus statement on the definition of orthostatic hypotension, pure autonomic failure, and multiple system atrophy. The Consensus Committee of the American Autonomic Society and the American Academy of Neurology. *Neurology*. 1996;46:1470



**September
11 & 12**

Step up for Parkinson's!



Get ready to to walk with us, Saturday, September 11 & Sunday, September 12, and join individuals, families, neighbours and friends at one of nine Alberta locations as we celebrate as a community and take action at the 9th annual Flexxaire Parkinson Step 'n Stride, our largest fundraising event of the year contributing more than 20% of our annual budget.

As a leader in pursuit of a better today and tomorrow for those living with and affected by Parkinson disease and Parkinson's Plus Syndromes, Parkinson Association of Alberta plays a critical role in addressing the needs of our Parkinson's community. By participating in and/or supporting Step 'n Stride, you are helping to ensure we can continue to deliver vital support and services to all Albertans as well as aim for a brighter future through research.

How we walk!



This year, participants will have the choice of joining us and many others to walk together in a safe and open environment, or going virtual and walking wherever they are!

Enjoy friendship, games, food and prizes along the 1km, 3km and 5km courses at each location (may vary by community) .

Your fundraising efforts contribute to the emotional, social, educational and active support provided by Parkinson Association of Alberta.

Visit parkinsonassociation.ca/step-n-stride to register and get started today

Pull out registration/pledge form on back page of this publication

September
11 & 12



FLEXXAIRE

PARKINSON



Want to help out?



We are always looking for volunteers to help us on walk day, as well at other PAA events.

Volunteer forms can be found on our website under the "Get Involved" tab, or better yet, contact your Client Services Coordinators or call 1-800-561-1911 to get involved!

Register early!



The sooner you get started, the more money you will be able to raise.

Rates of diagnosis will double in the next 10 years and with your help, we will continue to be able to meet the needs of our community.

Start your team now, and begin planning your fundraising strategy. Create your own fundraising page at parkinsonassociation.ca/step-n-stride.

Saturday, September 11

Edmonton

Rundle Park (Family Ctr.)

Calgary

South Glenmore Park

Red Deer

Golden Circle Seniors Ctr.

Lethbridge

Henderson Lake Park

Lloydminster

Bud Miller Park

Sunday, September 12

Camrose

Jubilee Park

Medicine Hat

Kim Coulee Park

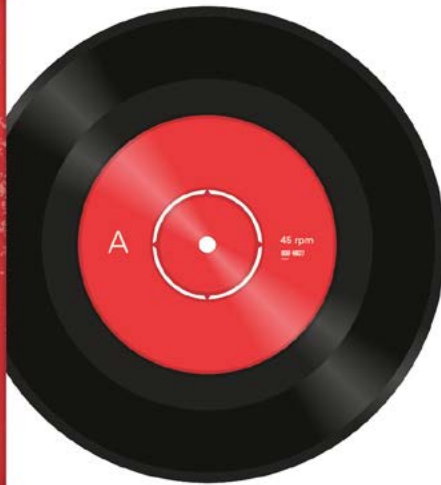
Cochrane

Mitford Park

Grande Prairie

Muskoseepi Park Pavillion

*For health & safety reasons, registration times will be staggered this year, please select your registration time at parkinsonassociation.ca/step-n-stride



Olfactory Dysfunction

Written By: **Jordan Weibe**

The words “Ageusia” and “Hyposmia” sound like something you would order at a fancy, exotic, high-end restaurant. However, these words refer to the loss, or reduced ability to taste (ageusia) and smell (hyposmia), a common non-motor symptom seen in Parkinson disease. This symptom may also be referred to as “Olfactory Dysfunction” by your practitioners. The loss of smell may be one of the earliest symptoms of Parkinson's, appearing much earlier than any motor symptoms. Around 90% of people with Parkinson's experience olfactory dysfunction¹, however, it is often unnoticed until a diagnosis is made. Looking back, many people realize they experienced this change several years before diagnosis.

When the ability to smell is reduced, so is the ability to taste which can have a big impact on an individual's quality of life.

Our senses are referred to as “The Big Five” for a reason; they are a big part of daily living. When one of those senses is impaired, it can have a pretty big impact on how we live our lives. Smell is important in allowing us to detect and identify a variety of scents daily as we smell food, the environment, and other people. Scent is also a key sense in helping us detect danger of rotten food or environmental hazards like fire and can also trigger memories of important moments in your life. Additionally, changes in taste and smell may lead to a change in appetite causing weight gain or loss, which may further impact your quality of life. If you are noticing any of these changes, it is important to reach out to your doctor.



What causes a loss of taste and smell?

Many of the earliest non-motor symptoms that develop as a result of Parkinson's are quite mild initially and slowly worsen over time. Just like how we do not know what causes Parkinson's, scientists are not exactly sure what causes the loss of smell. It is thought that the reduced ability to smell is caused by the breakdown of the olfactory bulb (the part responsible for detecting smells and taste) in the brain. The loss or reduced ability to taste is often a consequence of the reduced smell.

What treatments are there?

Currently, there are no treatments or medication that can be used to treat this symptom. The good news is, this is not a dangerous symptom, but it is important to continue to eat full balanced meals to make sure you get all the required nutrients. While there are currently no treatments for olfactory dysfunction, researchers are looking at it to identify people who may be at risk of developing Parkinson disease earlier as it is present before motor symptoms appear.

The loss of smell and taste can fundamentally change the way we experience the world around us, and it is okay to struggle with the loss of these senses. Sometimes, you may no longer be able to enjoy what was once your favourite meal, or you might not be able to smell your favourite flowers. These losses can be hard and should not be easily dismissed because they are crucial to some of our favourite, most memorable things. If you are experiencing any challenges with your non-motor symptoms, especially with the loss of smell and taste, know that you are not alone. We are here to support and help you navigate this ever-changing journey.

References

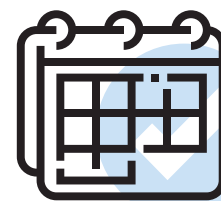
¹Rodriguez-Violante, M., Ospina-Garcia, N., Perez-Lohman, C. & Cervantes-Arriaga, A. (2017) Spotlight on olfactory dysfunction in Parkinson's disease. *Journal of Parkinsonism and Restless Legs Syndrome* (7) 33-41.

WHAT'S NEW?



Important Dates to Remember

- All PAA Offices will be closed for statutory holidays on the following dates:
August 2 (Heritage Day),
September 6 (Labor Day) and
October 11 (Thanksgiving).
- Flexxaire Parkinson's Step 'n Stride Walk Weekend is September 11 & 12
- We've missed you!! Summer Socials are taking place now! Check the Support Group listings for dates and call us to register!!



**PUT THIS ON
YOUR CALENDAR!**

New Support Groups



Over the past eighteen months we have had Care Partners from across the province ask to keep an online support group even after the pandemic was over. You ask, we deliver!

Beginning this Summer we will offer not one, but **TWO** Care Partner

Support Groups online – one morning and one afternoon. These groups are accessible via ZOOM or by calling in.

Maybe you don't have an in-person support group near you. Maybe you have a group near you but would like to connect with peers more often. Maybe getting to an in-person group is too hard. Whatever your reason – we are happy to add these groups to our provincial line up!

Please see page 14 for more details!

Ambiguous Loss Program

Ambiguous loss is a loss that occurs without closure or clear understanding. This kind of loss, like a Parkinson's diagnosis, can:

- leave a person searching for answers,
- complicate and delay the grieving process, and
- result in unresolved grief.



And, as Parkinson's is progressive, the losses continue with a degree of uncertainty and unpredictability.

To help our clients and their loved ones, we are excited to announce we have created a three-part program series to navigate ambiguous loss and learn valuable coping strategies. It is our aim to run this program in the Fall. Program size is limited, so if you are interested in participating in this program contact your Regional Client Services Coordinator or call us toll-free at **1-800-561-1911** to be added to the wait-list.

NEW HORIZONS FOR SENIORS PROGRAM



Projects Making a Difference in the Lives of Seniors

Canada

Announcement

We are happy to announce that we applied for and received a grant from the Government of Canada's New Horizons for Seniors Program of \$11,250. This funding was received for our direct Client Services Support and Education Programs!

REMINDER: Advance **REGISTRATION** is **REQUIRED** for each and every Support Group. Support groups may not run if no registrations have been received.

Please note that Support Groups will not run on statutory holidays.

PROVINCIAL (ZOOM/CALL-IN ONLY)	1-800-561-1911
1st Tuesday – DBS/Duodopa	1:00PM
1st Thursday – Widows/Widowers	9:30AM
2nd Monday – Care Partners AM (new group)	9:30AM
2nd Wednesday – Under 55	7:00PM
3rd Thursday – General Parkinson's	10:00AM
3rd Thursday – Care Partners PM (new group)	1:30PM
3rd Saturday – Parkinson's Plus	12:00PM
CALGARY REGION	403-243-9901
AIRDRIE	
3rd Tuesday	10:00AM
CALGARY	
1st Tuesday – Northwest	10:00AM
1st Thursday – Northeast	10:00AM
3rd Tuesday – Care Partners	1:30PM
3rd Thursday – Southwest	10:00AM
4th Tuesday – Southeast	10:00AM
4th Tuesday – Young Onset	7:00PM
CANMORE	
2nd Thursday	1:30PM
COCHRANE	
2nd Thursday	10:00AM
NANTON/HIGH RIVER	
4th Thursday	10:00AM
STRATHMORE	
1st Thursday	1:30PM
EDMONTON REGION	780-425-6400
CAMROSE	
2nd Wednesday	3:30PM
EDMONTON	
1st Wednesday – South	1:00PM
1st Thursday – Care Partners	10:00AM
3rd Wednesday – Central	7:00PM
FORT SASKATCHEWAN	
4th Tuesday	1:00PM
LEDUC	
4th Tuesday	6:30PM
PARKLAND (Spruce Grove/Stony Plain)	
4th Thursday	10:00AM

EDMONTON REGION...continued	780-425-6400
SHERWOOD PARK	
2nd Tuesday	1:00PM
ST ALBERT	
3rd Tuesday	10:00AM
WESTLOCK	
3rd Thursday (new day & time)	10:00AM
WHITCOURT	
3rd Thursday (new day & time)	10:00AM
GRANDE PRAIRIE REGION	780-882-6640
GRANDE PRAIRIE	
2nd Wednesday	2:00PM
LETHBRIDGE & MEDICINE HAT REGION	403-317-7710 403-526-5521
LETHBRIDGE	
3rd Thursday	2:00PM
MEDICINE HAT	
4th Thursday	1:30PM
SOUTHERN ALBERTA (ZOOM/CALL-IN)	
2nd Thursday	2:00PM
LLOYDMINSTER REGION	780-808-5006
BONNYVILLE	
3rd Tuesday	10:30AM
LLOYDMINSTER	
4th Tuesday	2:00PM
VERMILION	
2nd Tuesday	1:00PM
RED DEER REGION	403-346-4463
CASTOR	
4th Tuesday (Feb, May, Aug & Nov)	1:30PM
LACOMBE	
4th Wednesday	10:00AM
OLDS	
2nd Wednesday	1:30PM
RED DEER	
3rd Wednesday	10:00AM
ROCKY MOUNTAIN HOUSE	
2nd Thursday (Jan, Mar, May, Sep & Nov)	2:00PM
THREE HILLS	
3rd Thursday (new day & time)	10:00AM





Bladder Dysfunction

Written By: **Courtney Ukrainetz**

Parkinson disease has many different symptoms. One of the most common non-motor symptoms that people living with Parkinson disease face is bladder dysfunction.

The bladder has two main roles: to store urine produced by the kidneys and to periodically eliminate urine from the body. A healthy person urinates four to six times a day. It is estimated that bladder dysfunction affects up to 80% of individuals living with Parkinson disease, particularly later in the progression of the disease. The loss of dopamine can mean that messages telling the bladder to retain or expel urine may be disrupted.

The most common bladder dysfunction symptom in people with Parkinson's is overactive bladder. Some other common types of bladder dysfunction are urgency, meaning when you have to go, you have to go now, or frequency which means you have to go more often than most people. Other bladder dysfunction issues include nocturia, voiding issues, storage issues, and incontinence. Sometimes, increased urgency and frequency may be part of aging, but it is important to talk to your doctor to see if any bladder dysfunction you may be experiencing could be due to your Parkinson's.

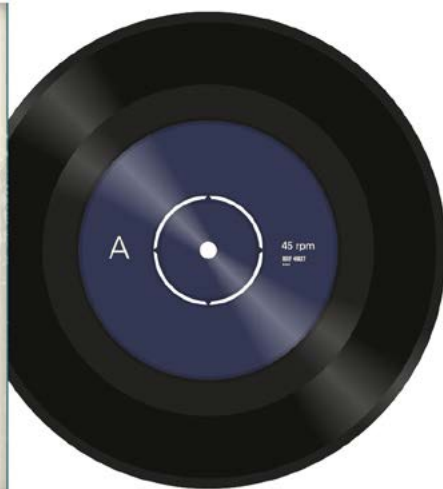
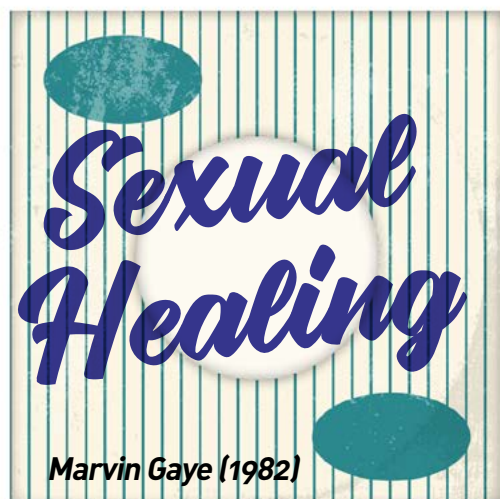
Just like most symptoms of Parkinson disease, it is important to seek medical attention if any of your symptoms of bladder dysfunction are affecting your quality of life. Your family doctor may be able to assist you or refer you to a specialist called a urologist. It may be helpful to write notes to discuss with your doctor, information about the type of difficulties experienced, the frequency of these issues, when you first noticed a change, and any normal eating or drinking habits. Some of these bladder dysfunction issues may cause other harmful effects on quality of life, for example, if you are struggling with urgency and mobility is an issue, a fall could occur if you are trying to rush to the washroom. Other difficulties could include trouble with clothing due to loss of use in the hands or tremor. Nocturia, the increased frequency to use the washroom at nighttime, could lead to sleep disruption and increased fatigue.

Individuals struggling with bladder dysfunction often try to restrict their amount of fluid intake due to worry about washroom needs. While understandable, it is important for adults to drink approximately eight to ten cups of fluids each day for efficient waste elimination. Some people find it helpful to get the majority of their fluid intake earlier in the day and restrict fluids closer to the evening and bedtime. Caffeine and alcohol can irritate the bladder and increase incontinence issues, so keeping these to a minimum may be beneficial.



It is important to note that not all people with Parkinson's will develop bladder dysfunction. Some treatment options for bladder dysfunction may include medications, botox injections, or even surgical interventions if necessary. A physiotherapist or an occupational therapist may be useful in the treatment of bladder dysfunction. A physiotherapist can assist with pelvic floor exercises, while an occupational therapist may be useful in some of the practical solutions such as clothing, grab rails, a portable toilet for nighttime, assistive devices, or a raised toilet seat etc.

References: *International Parkinson & Movement Disorder Society, European Parkinson's Disease Association (EPDA); nonmotor symptoms, PMD Alliance; Urinary Dysfunction in PD Webinar.*



Sexual Dysfunction Parkinson's

Written By: **Brandi La Bonte**

**Please be advised that this article contains what some may consider adult-themed issues and terms.*

Oh my goodness, now there is an opening line I never thought I'd write – a warning; but here we are and here we go... let's talk about S-E-X. Or, more specifically, sexual dysfunction as it pertains to the non-motor symptoms in Parkinson disease.

I know this isn't an easy topic for everyone to discuss, but it is a necessary and valuable one. For some people talking about sex or sexual dysfunction is an embarrassing or taboo topic. *(I get that, but it doesn't have to be)*. For some talking about or even being interested in sex feels inappropriate due to age or illness. *(It 100% is NOT)*. While others may be unaware that their sexual dysfunction may be related to Parkinson's or it's treatment. *(It absolutely can be)*. Whatever your reason for not wanting to talk about sex (with your loved one, a healthcare professional or other support person), I respect it AND hope to offer some insight and knowledge to help you and your loved one deal with this delicate and frustrating issue.

From a non-motor symptom perspective, sexual dysfunction occurs in both men and women. For men, erectile dysfunction (ED) is the most common sexual issue. For women it is vaginal dryness; while both sexes may experience orgasm difficulties and low libidos.

So why does this happen? Remember the autonomic nervous system we talked about earlier? Much like your bladder, sexual responses are an involuntary activity coordinated by your autonomic nervous system. When autonomic dysfunction occurs these functions (erections, bodily secretions, orgasms, and libido) can be negatively impacted.

Erections

The science/facts: In order to achieve erection, healthy nerve pathways and blood flow to the penis are necessary.

What happens when there is autonomic dysfunction:

Erectile dysfunction occurs when the nerve function and/or circulation to the penis is compromised. When this happens, men experience a difficulty in achieving and/or maintaining an erection.

What can you do about it: Your treating physician may prescribe medications (oral or injectable) for erectile dysfunction or refer you to another specialist such as a urologist for help managing erectile dysfunction. A vacuum pump device may be an option for men who do not want to or are unable to take ED medication; be sure to speak with your physician to discuss whether this treatment option is right for you. A surgical option may be available (penile prosthesis implant) as a last resort.

Bodily secretions

The science/facts: The main function of a man's prostate gland is to secrete a fluid that makes up approximately 70% of one's semen; in women, the Bartholin glands inside the vagina help lubricate to prevent excessive dryness.

What happens when there is autonomic dysfunction:

The body's natural ability to stimulate these secretions is negatively affected by autonomic dysfunction. Vaginal dryness can lead to significant pain during intercourse and also may result in bladder infections.

What can you do about it: There are many over the counter lubricants that can be applied to reduce dryness and discomfort; these should be water-based and not contain scents or artificial colors. Your pharmacist can help you choose the right one. In some cases your physician may prescribe hormone replacement therapy.



Orgasm

The science/facts: In describing orgasms as it relates to non-motor symptoms, orgasm happens when the genital and pelvic muscles experience rhythmic contractions approximately 0.8 seconds apart for on average from 10 to 30 seconds. It is important to note that orgasm does not occur for everyone.

What happens when there is autonomic dysfunction:

Orgasm difficulties can occur when the nerve function to the genitals and pelvic muscles are compromised.

What can you do about it: Sometimes addressing the physical issues of erectile dysfunction and/or vaginal dryness make it easier to achieve orgasm. Having an honest discussion with your treating physician, clinic nurse or a clinical sex therapist will also be helpful.

Libido

The science/facts: The parasympathetic nervous system is directly involved in the process of sexual arousal.

What happens when there is autonomic dysfunction:

Issues with a low libido/sex drive can occur when nerve function is compromised. It is important to note however that there are many other factors in Parkinson disease that can contribute to a diminished libido (read on).

What can you do about it: It is best to speak to your treating physician about this issue as it may be that it is one of the other contributing factors causing your low libido, and not autonomic dysfunction.

Other factors that may cause sexual problems for a person with Parkinson disease include, but are not limited to: decreased dopamine levels, some Parkinson's medications, other physical difficulties in Parkinson's such as rigidity and pain, depression, anger and grief, stress, problems with body image or self-esteem, and disease-related fatigue. Parkinson's may also affect your partner's sexuality as well.

Over HALF of people with Parkinson's report that their sexual life and desire has been negatively impacted by the disease. Unfortunately, because of the aforementioned reasons (embarrassment, lack of knowledge, etc), many people do not raise these issues with their neurologist or doctor. This under-reporting also means that research into sexual dysfunction and Parkinson's is not as complete; with current research suggesting that sexual dysfunction is prevalent in the broad range of 37-65% of people with Parkinson disease¹.

Intimacy and a healthy sex life are an important part of human connection and relationships, regardless of illness or aging. If this is something you or your loved one is struggling with it is important to not only talk to each other, but to ask for help from a medical professional as there are many things that can be done to maintain intimacy and a healthy sex life.

References

¹ Bronner G, Royter V, Korczyn AD, Giladi N: Sexual dysfunction in Parkinson's disease. *J Sex Marital Ther* 2004;30:95-105



Restless Legs Syndrome

Written By: **Brienne Leclaire**

Restless legs syndrome (RLS) is characterised by a discomfort in both legs and an intense urge to move them. This discomfort may include unpleasant sensations such as pain, burning and/or pins and needles in the legs or feet (though it can also affect the arms, head, and other parts of the body). These sensations have been described by people with RLS as feeling like “fizzy soda is bubbling through their veins”, “creepy crawly feeling” or like a “deep bone itch.” Symptoms typically begin when individuals are at rest, alleviate when they are moving and, gets worse specifically at night. In fact, symptoms typically only occur in the evening and night, making restless legs syndrome a sleep disorder as well as a movement disorder. Restless legs syndrome significantly interferes with rest and sleep, which in turn can seriously compromise quality of life.

Though the exact cause of RLS is unclear, many researchers believe that it “may be caused by an imbalance of the brain chemical dopamine, which sends messages to control muscle movement.”¹

Restless legs syndrome is a condition separate from Parkinson disease as it occurs in both people with and without Parkinson disease. Restless legs syndrome affects about 7-10% of the general population. However, because RLS and Parkinson disease both respond to the drug dopamine, researchers have looked for connections between the two disorders. Some studies have shown that people with Parkinson’s are more likely to have restless legs syndrome than people who don’t, though this hasn’t been proven conclusively at this time. People with Parkinson disease may have difficulty getting diagnosed with RLS as symptoms may be sporadic or confused with other symptoms related to Parkinson’s – such as those that occur when one’s medications are wearing off.



Managing Restless Legs Syndrome

Managing RLS can be done in a variety of ways. Certain drugs have been shown to manage the symptoms of RLS; and in some cases, RLS has been linked to iron deficiency. A doctor may recommend medications, supplements or vitamins to help alleviate symptoms. There are some non-pharmacological approaches as well. Finding the right amount of exercise can help alleviate RLS. Avoiding stimulants like coffee, alcohol and smoking may also help reduce symptoms. Creating a cool and peaceful sleep environment can help reduce symptoms and promote better sleep.

There are also many anecdotal home-based tips one can try to help alleviate symptoms, including:

- stretching and massaging the legs;
- applying a hot or cold compress to the legs;
- taking a warm bath before going to bed;
- soaking your feet in hot water prior to sleep;
- wearing compression stockings or tights in bed; and/or
- placing a pillow between your knees or thighs when lying in bed.

References

¹ Mayo Clinic, Restless Legs Syndrome, <https://www.mayoclinic.org/diseases-conditions/restless-legs-syndrome/symptoms-causes/syc-20377168>



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